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Ilario Toniello

The potential role of medical imaging to support treatment decisions

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Supervisor: Professor Marko Nieminen, Aalto University

Advisor: Dr David Gilmore, Elekta

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Aalto University **School of Science** **Master's Programme in ICT Innovation**	**ABSTRACT OF THE MASTER'S THESIS**

Author: Ilario Toniello

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Abstract:

The treatment of cancer has received great advantage from medical imaging technology. This thesis project is oriented to collect the opinion of patients and medical personnel to understand if advanced medical imaging could be useful when patients are involved in treatment decision making (TDM) process. In the specific, the investigation tries to understand if medical imaging can be useful for TDM in patients affected by prostate and bowel cancer and at which degree. The project was conducted with semi-structured interviews involving medical personnel. The opinion of the patients was collected with the analysis of patient's diaries shared on the Internet. A thematic analysis was performed to both sources to extract valuable insight about the problem. The results of the research shows that, at the current state, medical imaging is difficult to be used to guide patients in treatment decision making. In particular, the research revealed that medical imaging is underused due the difficulty to collect, organise and show medical pictures. Nevertheless, imaging is a powerful tool to help TDM in some specific situations. Body scans and other imaging techniques look promising tools for TDM, but further investigation is suggested to discover its full potential.

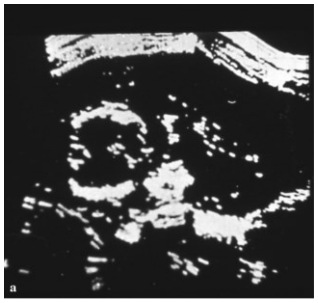
Keywords:

Colorectal cancer, Diary research, HCID, Human-computer interaction design, Interviews, Medical imaging, Oncologists, Patients, Prostate cancer, Thematic analysis, Treatment decision making

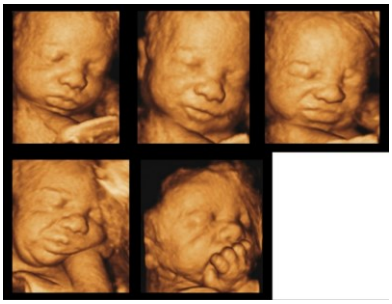
Table of contents

2. Introduction

Medical imaging is a process that allow to visualise internal organs and tissues of the human body in order to diagnose and treat diseases. One of the early medical imaging methods is x-ray photography (radiography), discovered at the end of the XIX century (Price, 2001). Since that time many other methods have been developed to see inside the human body. Imaging evolved with the discovery of new physical waves that can travel through the body and generate visual information, for example nuclear imaging, PET magnetic resonance, MRI, or sound waves (Morris & Perkins 2012, April). The evolution of these techniques includes even the way that the scansion of the body is performed, for example with the invention of the tomography process that allow to scan the body in “slices” and reconstruct the visualisation in a virtual 3D representation (Webb, 1988). The quality of imaging has been greatly improved since the introduction of this last technology in the medical field. Nowadays, the most sophisticated technology visualises in real time the activity of the human brain or helps doctors to perform delicate surgery operations on internal organs (Morris & Perkins 2012, April). However, body scan images require special training to be read. For this reason, the visual result of a body scan is generally kept for the eye of the experts, and patients do not have access to this kind of information. Nevertheless, this situation is changing. Medical equipment technology is improving and the readability of these special images is going to be more accessible in the near future (Doi, 2007). For example, exploration of fetus through ultrasound imaging was quite primitive in the early stage of the use of this technology. Nowadays, 4D high resolution ultrasounds are performed also as leisure activity or to help mothers to establish a bond with the expected baby (Campbell, 2013; Figure 1). The purpose of this thesis research is to collect information to understand if similar high quality medical imaging can be understood by non-experts in the treatment decision making of prostate and bowel cancer.



Ultrasound in 1972



Contemporary 4D ultrasound

Figure 1: a comparison of ultrasound images[1]

This research is planned to investigate on this topic with the help of Elekta[2], a Swedish company that provides medical equipment for cancer treatment and body scanning.

2.1 The research question

The research question that is investigated is: **"Could medical imaging be a valuable tool in helping prostate and bowel cancer patients to engage more effectively in treatment decision making? If so, how?"**. To reach this purpose, it is collected information by investigating two different fronts. Firstly, it is collected the opinion of doctors with qualitative semi-structured interviews. Secondly, it is collected the opinion of patients through public online sources. The information gathered from both channels are analysed through a thematic analysis. The analysis shows that medical imaging are underused in the current medical practice. Doctors consider images too complex to be handled by patients, but the main factor that prevent a wide use of images is the difficulty to search and review medical imaging with the tools currently provided by hospitals and medical facilities.

1 ncbi.nlm.nih.gov/pmc/articles/PMC3987368

2 elekta.com

3. Literature Review

The study of cancer phenomena has produced a vast literature. A deep knowledge related to this topic can be useful, however for the purpose of this brief study is important to concentrate in few themes that have come to light during the research of information about prostate cancer treatment decision making. Firstly, it is essential to analyse the specific conditions that make crucial the involvement of the patient and the family in prostate cancer treatment decision making (TDM). Bowel cancer has many similarities with prostate cancer but many differences as well, for this reason both diseases are presented briefly. Then, this research presents basic information about the doctor-patient relationship and how it has evolved during time. It is also important to draft the new role of patient in TDM and how web resources changed the way patients face a disease. Furthermore, it is considered the remarkable role that patient's companion has in treatment decision making in the specific case of prostate cancer. The last topic that is presented explores the relevance of the web as source of patients' opinion.

3.1 The reason to focus on prostate and bowel cancer

Cancer is one of the greatest medical challenges. The complexity of cancer and the difficult treatment approach make this disease arduous to manage for doctors, patients and the family of the ill ones (Degner & Sloan, 1992). During the last years new discoveries and progress of technologies have offered new powerful tools and treatments against cancer. For this reason, mortality of patients decreased in a significant way (Siegel, et al., 2016, p. 13). Prostate cancer (PC) is a disease that stand out other forms of tumorous illness. PC has special attributes that make it a special case study when it is considered the involvement of patient in treatment decision making. First of all, in developed countries PC is the most common form of cancer diagnosed in men. It is quite uncommon in men in their forties or younger, however the risk to develop this disease increase by age starting 50 years old (Jemal et al., 2011). Luckily, there is a wide range of effective medical therapies available, but none of them can promise an effective cure, and therapy's side effects can be extremely debilitating. In case of positive diagnosis, the usual preferred

intervention is a “watch and wait” strategy, especially for aged patients that have to deal with a multiplicity of diseases at the same time (Catalona, 1994).
The colorectal cancer (CRC), more commonly called bowel cancer, is a form of cancer that attacks the terminal part of the digestive system, the colon and the rectum. Like prostate cancer, it is a common form of tumorous disease, the third most common for both men and women (data related to estimated number of cases in US during 2016, Siegel, et al., 2016, p. 11). The big difference between PC and CRC is that the first one is a gender-related disease because it affects only man, while the importance of CRC is its universal spread between people, even it is just the 8% of the whole number of estimates cases of cancer in US (Siegel, et al., 2016, p. 11). Great attention is given in early detection of this form of cancer. Since mid 1980s, there has been a great decrease of mortality, and statistically this is due the introduction of screening and the decision of early intervention to remove detected precancerous lesions (Siegel, et al., 2012). The use of colonoscopy increased in people aged between 50 and 75 from 19% in 2000 to 55% in 2013 (Centers for Disease Control and Prevention, 2014). Another difference between PC and CRC is the ability to easily detect the disease. PSA (free prostate-specific antigen) is a commonly accepted indicator of the risk of prostate cancer and it can easily be detected and monitored with a simple blood test (Partin et al. 1996). Unfortunately, there is not an equivalent sign in bowel cancer because there are different origins of the colorectal cancer. For example, Popat et al. (2005), classified CRC in two main categories by proposing the molecular marker microsatellite instability (MSI) as differentiating factor. Colorectal cancer cells positive to MSI have a different growing behaviour compared to the one that do not express this marker. However, many other studies proposed different other markers and there is still disagreement between the experts on this topic (Tsuji et al., 2003; Allegra & Sargent, 2003; Popat et al., 2004). A further important factor that drives this research on the topic of bowel and prostate cancer is the collaboration with the company Elekta as project advisor for this thesis research. Elekta is an international company, specialised in medical equipment for body scan and cancer treatment[3]. The treatment of bowel and prostate cancer is one of the problems where the company invested the most, for example for innovative technologies that mix real time body scan to cancer

[3] elekta.com

treatment[4], or brachytherapy intervention (a kind of cancer treatment that involve the placing of radioactive capsules in a specific position into organs with long needles). The opportunity to have an inside contact in the industry strongly conditioned the choice to focus in PC and CRC.

3.2 The bond between patient and doctor

It is significant to understand the general relationship between patient and doctor over time in order to comprehend the importance to involve patients with prostate cancer in treatment decision making. Previous studies on TDM (Davison, 1997; Wong et al., 2000) showed that patient's activity in case of therapy decision follows three main cases:

- Active or autonomous TDM: in this case the patient has full decision and responsibility in the therapy to take. Doctors and experts have just a consulting role. This approach is quite uncommon;
- Shared or collaborative TDM: decisions about the therapy are equally shared between doctor and patient; and
- Passive TDM: medical personnel take full decision about the cure to follow.

Further investigations showed that patients generally appreciate to have the possibility to choose their therapy. This is particularly true for PC patients (Ford et al., 2003). In Ford's research, the opinion of 171 patients treated by GPs was taken in account. The data collected showed that two third of the participants wished to have some form of control in TDM, with the 47% that wished to share the therapy decision with the doctor and the 18% that desired to take full control in decision making. It is also important to note that the 35% (one out of three) of the participants preferred to leave to health care experts the full mastery of the treatment, so the sentiment to leave the decision to the hands of the doctors is not uncommon. Similar preferences were found in another study (Gattellari et al., 2006). Both researches, though, enlightened a discrepancy between the control that patients wished and the real decision power that doctors and medical personnel allowed to release to the patients. In Ford et al. (2003) only the patients that were looking for a non-active role were largely satisfied, with the 64% of them that obtained the wished TDM option. Doctors agreed with the 52% of the patients that wished to share and only the 41%

[4] elekta.com/brachytherapy

of the ones that aimed for the active control of the treatment. Gattellari et al. (2006) found similar data. In the research of Gattellari et al., the 29% of the patients felt to be too active and the 37% that felt less engaged than wished. Patients that desired to have less control in the decision were largely gratified, and this shows how the medical personnel still aim to keep a tight control in treatment decision making. The lack of satisfaction in TDM can be a big problem in cancer therapy because several researches (Cohen & Lazarus, 1979; Marks et al., 1986) showed that patient's satisfaction in DTM increase the positive psychological effect of self-efficacy and the capacity to manage the illness. Patients that are not allowed to participate to TDM are excluded from this potential benefit. The majority of the studies in this sector showed that to give to the patient the right to decide how to manage the treatment is the most positive outcome if the patient wish to take more control on it.
Unfortunately, to treat a disease is a complex activity and patient's opinion can change once the treatment enter in a more difficult phase. This is particularly relevant in case of complex diseases like prostate cancer. For example, Davison & Goldenberg (2003) completed a study with participants affected by PC. The 94% of them accepted an active role in treatment decision (collaborative or fully active). This is a remarkable result, however the participants were chosen from a pool of people that previously participated to an experiment that aimed to increase the feeling of autonomy in cancer treatment and increasing of the feeling of self-efficacy. This choice shows how easy is for external entities to manipulate patients' opinion.
Furthermore, it was demonstrated that TDM wishes can change over time. Cohen & Britten (2003) monitored patients that chose one on the three previously mentioned treatment roles. They discovered that patients that chose a passive role at the beginning of a treatment were the ones with the higher level of satisfaction, however for this group of participants the gratification of the chosen role decreased over time. Patients with active and shared roles showed a similar opinion at the beginning of a treatment but lately the gratification of the chosen role remained substantially stable. A detailed study by Fischer et al. (2006) verified this effect with patients affected by prostate cancer. Fisher's team considered many variables, looking for a correlation. For example, it was monitored the stage of the disease, how the participant was involved in TDM, therapy satisfaction, age and other characteristics. The study showed that patients are willing to be considered in the treatment decision process. Furthermore, the result of the research evidenced that participants that chose a

shared/collaborative or an active treatment decision role were the ones more satisfied, especially the youngest patients. Patients that felt more involved in TDM were the younger in their early stage of the disease, while older patients felt that their treatment wishes were not considered by the doctors.
To summarise, the literature in investigation about patient-doctor relationship shows an intricate situation where patients are fighting to find their new role, and in the same time doctors are reluctant to share the decision power that they fully manage by tradition.

3.3 Why patient's opinion matter

There are few important causes that make prostate cancer a disease in which the opinion of the patient must be considered during treatment decision making. All these causes are related to the particular progress of the disease. McMurtry & McMurtry (2003) drew a comprehensive and yet concise report of these conditions. Firstly, the initial stage of prostate cancer is generally asymptomatic. Patients who are diagnosed to have PC in this stage are generally recognised sick by chance. Only in late stages there are symptoms perceived by the patient that can help experts to identify the disease. It is possible to take action with radiotherapy or surgery in case of tumors that are delimited in a small area. Radiotherapy can be administered via radiation beam, however a common practice is brachytherapy. Brachytherapy is a procedure that consists in the implantation of radioactive capsules directly into the organs via long needles. This practice is favourite in case of prostate cancer because the prostate is an organ that has high mobility and brachytherapy allow to aim a precise portion of tissue of the organ. There are not cures currently available in case of metastasis. It is proved that the administration of hormones can slow down the disease if other more invasive treatments are not chosen. In case of old patients or in case of comorbidity it is preferred to do not intervene and just monitoring the progress of the disease. This cautious approach is due the deep side effects of all the possible treatment options. For example, erectile dysfunction and incontinence are common side effects of the surgery approach; radiation therapy has some side effects that accumulate over time; and lastly, hormone administration causes downsides on libido and sexual life. In conclusion, the involvement of patients in the treatment decision making is paramount due the

lack of an ideal treatment and the high cost in term on psychological and emotional effects during the therapy (Catalona, 1994).

3.4 The e-Patient new era

The passive role described in chapter 3.2 is the one that patients are traditionally taking. In other words, in past time the part that patients were taking in treatment decision making were mainly submissive (Fischer et al., 2006). Recently this approach started to change and patients are assuming a more active role in TDM (Wong et al., 2000).

A clear pattern in the patient-doctor relationship in treatment decision making emerges from the previous analysed literature. In some situations the patient can take control of TDM, in some other circumstances the patient has less power in cure planning. However, the presence of the doctor is always a constant parameter in the treatment decision making process. The raise of the World Wide Web as main communication channel disrupted the physician-patient archetypal relationship. Moreover, new TDM information started to flow between experts and patients and between patients thanks the Internet and other new digital media. One of the most successful stories is the tale of Dave "e-patient" deBronkart[5]. Moreover, on the Web there has been a flourish spreading of blogs, forums, and electronic newsletters. These channels have become the tools for patients, researchers and experts to share information in an innovative way. As deBronkart (2015) pointed out, health care professions required skilled people and years of training to be mastered. For this reason, the common adage "doctor knows best" well summarise the way that medicine was practiced during the centuries. Nevertheless, new technologies have helped patients to link each other and involve them actively in decisions about the strategy to take in the cure of their diseases. deBronkart speaks from a personal perspective due the fact that he was diagnosed to have cancer. As he reported (deBronkart, 2015), "I didn't sit back and expect to be saved". He discovered a lively cluster of online forums and communities where patients like him connect between each other, share information, give and receive suggestions. A key factor that contributed to the evolution of the role of patients is the spreading of the Internet and the developing of novel technologies that have changed the traditional stream of

[5] https://youtu.be/oTxvic-NnAM

information. In past time, the only available information flow was “top-down”, from research labs and medical associations to doctors and medical experts, to land lastly to patients. Patient treatment decision possibilities were flattened by the lack of alternative sources and the imposed authority of physicians. At the present time, the flow of information is more similar to a network. Patients, experts, researches, institutions, doctors, and pharmacy companies are connected points of a huge web and all of them support treatment research with their unique abilities (Basset et al., 2012). The need of information is common for all the patients, however the ones that engage more online looking for treatment clues are people that suffer of chronic disease like cancer (Fox, 2008). Furthermore, more than the 50% of the adult Internet users are accustomed to research online for healthcare information. These factors make the e-patient practice the third most common activity on the Web (Klass, 2004).

3.5 Masculinity and spouse’s special role in prostate cancer TDM

Prostate cancer (PC) is a disease that strongly involve social and cultural aspects of masculinity for several reasons. Firstly, it is a condition that affects only men. Moreover, treatment options have side effects that have heavy consequences of the urinary and reproductive systems. For these reasons, men feel particularly vulnerable. Wall & Kristjanson (2005) consider gender role and the cultural framework essential points to take in consideration in case of PC, because they can influence patients behaviour and attitude to treatment decision. The research field of gender role is wide and complex, and the purpose of this dissertation is not to focus in a deep research on this topic. Nevertheless, it must be considered that the most disrupting consequences of prostate cancer treatment include impotence, loss of libido and incontinence. These consequences threat the belief of masculinity of the patients because they limit the related principles of power, ability to withstand adverse conditions and independence (Chapple & Ziebland, 2002). The same principles make problematic for male patients to have a straight and open discussion with doctors about medical conditions that affect the reproductive system. It was proved that communication channels available via innovative technologies are useful instruments to overwhelm the social restrictions that adult males feel conditioned by

their social role (Broom, 2005). Moreover, many researches on this topic identified a special role of spouses in doctor-patient communication. Studies of the behaviour of couples that interact with physicians show that couples act like a “dual system” instead of two collaborating individuals (Hagedoorn et al., 2008). Furthermore, it was highlighted that spouses often assume the role of communication channel between the patient and the oncologist. Some gender role studies showed that is difficult for the patient to ask directly to doctors some questions about their health, so the spouse acts as a medium to ask questions and receive information from experts (Mason, 2005, May). This behaviour is a key aspect to consider in case of TDM research for prostate cancer. Nevertheless, it is important to know that the research in this sector is really limited, and explorative analysis discovered that the influence of gender behavioural schemas in TDM in case of prostate cancer is more complex than expected (Broom, 2005). As last consideration, it is noticeable that the available information in TDM of PC in case of single men or not traditional couples is scarce.

3.6 The web as opinion source

To use data collected from the web can facilitate the research, however it raises ethical challenges. Golder et al. (2017) analysed 17 different studies of ethical approach to the use of new media like social networks and web sources. The research led to conflictual results and demonstrated that it is complicated to design ethical practices for studies that involve sources from the Internet. Nevertheless, Golder et al. identified useful guidelines that can help to set the methods of a research based on web sources:

- The use of sources open to public, like comments and web pages, is more acceptable than the use of sources that require a registration and password for the access (e.g. closed forums, social networks, etc.);
- Internet users are favourable to publish aggregate data, they are less favourable to use direct quotations;
- Information consent is a major problem because it is difficult to have the direct consent from users. Often the consent is required during the registration process and it is reminded in the web source guidelines, however many users do not read all the information provided, and they are not aware to be monitored;

- To quote part of the source can be difficult because it is challenging to keep the source of the data anonymous when strings of text can easily researched and identified on the Internet;
- Overall, every research project should consider ethics guidelines based of the nature of the research (trivial vs sensitive topics), the type of data (aggregated vs qualitative), issues like anonymity, confidentiality, informed consent, privacy, and the right balance between risks and benefits.

Bond et al. (2013) contacted users that shared personal health information online and asked directly their opinion. Many participants showed a conflictual behaviour. They recognised that information shared on website is open to be read by everyone, also they have a positive approach toward the use of their information for research purposes and "for the good of the all". On the other hand, they still feel to retain the ownership and the right to use the shared information. In a research with users of Internet cancer discussion groups (Seçk, 2009; Taylor et al., 2014) it was noticed that the demographic characteristics of the users were different from the average composition of the population affected by the same disease. As consequence, the insight collected with these resources cannot be generalised in a quantitative way. The selection bias is due the nature of non-representativeness of the Internet user population, however another important bias effects are disclosure and concealing effects. In particular, forum users will to be proactive (e.g. participate to surveys, researches, etc.), but in the same time they share only part of the information at their convenience (Eysenbach & Wyatt, 2002; Taylor et al., 2014).

To sum up, studies about ethics in the use of sources from the Internet and social media show that it is not enough to apply the ethics protocols developed for traditional research when electronic data is used in a study. In future, new forms of ethics should be developed, for now researchers should take extra care in the development of the study protocols in order to include extra protection above the standard ethics approach (Bond et al., 2013; Golder et al., 2017).

3.6.1 Design a Thematic Analysis from web sources

Web resources can be an unique point of view of the opinion of the patients thanks to the nature of the Internet to share information in an equal way between the different users (chapter 3.4). Experience of previous researches conducted with

online sources can lead to a valid approach to design a thematic analysis from web sources. Herring (2009) studied exhaustively how a content analysis is differentially approached by the researches in case of online sources. The main point of her research is that online sources are different from traditional information channels. The main differences are: the possibility of posts in forum and blogs to be updated over time; to carry hyperlinks that extend contents to other sources; to let readers to comment the post and expand the original information; and to broaden the information with multimedia sources (e.g. videos, audio clips, etc.). Herring (2009) shows that traditional research approaches are limited, and that researchers tried different methodologies to overcome the boundary of traditional research systems. Unfortunately, a comprehensive approach does not exist and different study methods have been tried with alternate results. In conclusion, Herring suggests to do not limit the research to traditional and limited approaches, be flexible in the research with web sources while keeping a high research standard and a systematic content sampling and analysis, and to keep awareness in the limitation of the chosen approach. Gooden et al. (2009) compared women affected by breast cancer and men affected by prostate cancer that shared their opinion in online discussion boards. Gooden et al. research mainly focuses on similarities and differences between the two diseases, gender and other factors. Therefore, their methodology can be used as one of the references for this thesis research. Gooden et al. approach includes the selection of two specific databases to compare the two diseases and a specific time window to select the data for the analysis (one month). They decided for a traditional approach to the analysis based on the Grounded Theory with three phases: an early open coding; a further axial coding to re-arrange the founded coding; and a final selective coding that brought to the final categories. In conclusion, web as opinion source is a wide and still partially unexplored territory. The potential of this source for the research is significant, however there is still not consensus among researchers about the best research approach to take in this scenario, and many potential obstacles are present. Therefore, researches based on web sources should have a strong method design that include clear assumptions and limitations in the research plan.

4. Methods

Two different studies investigate the research question from two complementary points of view. A first investigation, based on semi structured interviews, is organised with experts in cancer treatment. A second study analyses data generated from patients and collected from the web.

Ethics approval and informed consent

This study has been approved by UCLIC Research Department's Ethics Chair (Project ID No: UCLIC/1213/015/Staff Blandford). The participants are informed about the purpose of the study and their rights follow the UCL guidelines for research with participants[6]. In particular, participants are required to sign an informed consent before to be interviewed for the study. Data from the web is carefully selected to be open to collection and anonymised during the analysis process in order to be compatible with the UCL Ethics Exemption Guidelines[7].

4.1 Study 1: The opinion of the experts

The first study investigates the involvement of patients in TDM process by collecting the opinion of experts. Oncologists are the obvious main category of experts to involve in the research. Oncologists do not spend a lot of time with patients like technicians, yet they use their expertise to set the therapy and check the result of the treatment (Caddy, 2000; Hurria et al., 2008). During the last years, a new sensibility toward the patients has been developed in the majority of oncologists. Many doctors have been deeply involved in improving the physiological condition of the patients, and they are trying to make the treatment process as much acceptable as possible for both the physical and the mental wellness of patients (Cherny et al. 2003).

4.1.1 Participants' details and inclusion criteria

Participants are selected with a convenience sampling (most accessible participants). It is also implemented a snowball sampling process (Blandford at al. 2016, p. 25) by asking to the doctors that are participating to the research to

6 https://ethics.grad.ucl.ac.uk/

7 https://ethics.grad.ucl.ac.uk/exemptions.php

introduce other potential participants to the researcher. It is considered acceptable any oncologists with previous experience of treatment with patients. It is excluded from the research oncologists that have not expertise in the field of prostate and bowel cancer. As many similar qualitative researches, it is hard to quantify the right number of participants required to collect enough data. It looks pragmatic to take into account six participants as minimum acceptable number considering the available time to collect and analyse data for a MSc thesis research (Blandford at al. 2016, p. 29). The same number is suggested by Guest et al. (2006). Through it is hard to generalise the result of a research about qualitative data saturation, the original data used by Guest et al. (2006) for their analysis is similar to the one of this master thesis study. In both cases participants are interviewed and open-ended questions are used. In Guest et al. (2006) the level of saturation was calculated by identifying the total number of new codes generated by the thematic analysis while new interviews were added to the research. The result showed that the 73% of the codes were added during the analysis of the first six transcripts. The following six transcripts increased the cumulative amount of codes to 92%. Further analysis added a negligible increment of new codes. The researchers concluded that the optimal saturation of the data is reached at twelve participants, while the basic elements for the generation of the themes were already reached with six participants. In conclusion, collect the opinion of a minimum six participants is enough for this research with the goal to reach an optimum of twelve participants.

4.1.2 The advantages of semi structured interview and thematic analysis

Data is collected with semi structured interviews and analysed with a thematic analysis. This is considered one of the best approaches to collect rich qualitative data due the explorative nature of the research question in the healthcare sector (*Tong et al., 2007)*. A qualitative research approach is also considered the best way to collect insight from complex situations that involve medical personnel (*Sandelowski & Barroso,2003).* Thematic analysis is particularly effective in situations where there is a limited access to participants and the goal is to obtain high quality information (Blandford at al. 2016, p. 40; Sharp et al., 2007, chapter 7.4). A qualitative analysis approach is also a good solution to gather information to

design a better experience for patients in TDM (Säde, 2001). In particular, this last aspect is the aim of this master thesis project as well.

4.1.3 Design

The semi structured interview is designed with: an introduction part that has the purpose to warm up the conversation and that informs the participants about their rights and ethic agreement; a main body that has the purpose to collect the majority of the information; and a conclusion part to summarise the findings and thank the participants. The questions and the developing of the interview will follow the general attention used during the collection of qualitative data, for example avoiding to preempt answers by suggesting that a particular answer is requested; to follow the structure of the interview plan but be flexible if the participants introduce new topic; and to use of probe questions to get more information of interesting topics rise during the interview. (Blandford at al. 2016, p. 40; Sharp et al., 2007, chapter 7.4.3). It is requested to the participants to focus in previous experience rather than imagining hypothetical general conditions.

Alterations after pilot test

A pilot test of the interview was conducted with an oncologist. The result showed that the first idea of a 40~60 minutes interview was completely unrealistic. First of all, doctors have a busy schedule and it is hard to be able to obtain such availability. Secondly, doctors are used to process a large amount of information and communicate to people in a fast and efficient way (Cegala et al., 1995; Ogden et al., 2004). Consequently, the pilot test showed that the whole interview was completed in less than 30 minutes without impact in the quality and the quantity of the searched information. Moreover, the participant was not able to focus on the interview for the whole time allowed for the conversation. During the pilot interview the participant had to stop the conversation and answer to an urgent call. The interview protocol was improved in order to consider this kind of event. The interview protocol was enriched with the possibility to take notes of the last part of the conversation to facilitate to start again the talk on the same topic in case of interruption. Furthermore, it was considered to organise the audiotape tool in a way to easily pause the record to preserve the privacy of the participant.

In conclusion, it was considered to allow 25~30 minutes for each interview and to change the research protocol to improve the privacy participant and to consider possible interruptions during the interview process.

4.1.4 Materials

The semi structured interview requires the use of recording tools. It will be used two recording tools in the same time to ensure that the recording will be at an acceptable quality and that there will not be failure in the registration process. A smartphone and a laptop will be used for the audiotaping. Double recording is performed to avoid the risk to lose the record in case of failure of one of the two devices. Both devices are password-secured and recorded files are transferred to an encrypted and password-protected folder to respect the research security guidelines. Materials is checked before the interview to be sure that they work properly (e.g. full batteries, available memory storage, etc.). Pens, paper sheets, post-its, notebooks, and other paraphernalia will be provided to facilitate to take notes and help participants to draw sketches or write memos if it would be useful during the interview. For the data analysis the interview will be transcribed and analysed with the application ATLAS.ti.

4.1.5 Procedure

Before the interview the materials is examined with a checking list to be sure that everything that is needed is available and that the electronic tools work properly. The interview script is used to guide the interview. Data is collected with audio recorders. Pictures can be taken with the phone camera if some visual material will be provided as example. Extra care is taken during the shot of pictures to avoid to record personal information or details that can potentially help to identify participants or other people. Photos are shown to the participant and it is asked the participant's verbal agreement to save the images, otherwise the file is deleted right away. At the end of the interview the participant is thanked and a gift of the value of £10 is given as form of compensation (high quality coffee or tea caddy). Visual material (like sketches produced by the participant) is collected, scanned and converted to a digital copy. The audio tape is transcribed and a thematic analysis is performed on it. Data is coded and early themes emerge from the codes clustering. Guest et al.

(2011) chapter 3, and Blandford et al. (2016) chapter 5.4, provide a summarised and useful description of the procedure. Affinity diagram method (also known as "K-J method") is performed to help the emersion of themes (Holtzblatt, 2001; Holtzblatt & Beyer, 2014; p. 24). It is followed the approach suggested by Courage & Baxter (2005) Appendix F ("Affinity Diagram" section, p. 744). In this phase the collected pictures can be used to support themes. The last part of the research consist in a re-arrangement of the themes with a final name and descriptions (Blandford et al., 2016; chapter 5.4). Relevant themes are used for the final report (chapter 5). Data (audio, transcription, text and working file) are anonymised and stored in an encrypted folder to respect UCL research guidelines.

4.2 Study 2: The opinion of the patients

This study collects the opinion of patients by analysing over a thousand diaries written by people affected by cancer. The diaries are collected from the web, and for this reason a particular attention has been used to ensure the right of safety and anonymity of the authors. Data are analysed through thematic analysis by looking for information that could help to answer to the research question.

4.2.1 The Web as data source for this research

To use the Web as source of patient's opinion is an approach that has several advantages. Firstly, the analysis of public and anonymised data on the web respects UCL ethic committee guidelines[8]. Furthermore, this study completes the opinion of experts collected via the analysis of semi-structured interview (Study 1).

4.2.2 Sources selection criteria, ethic guidelines

The selection of online resources is extremely important in order to respect UCL Ethics rules[9]. UCL requires specific conditions of exemptions of the request of Ethics clearance in case of online sources[10]. In particular, the exemption is valid for: "public resources freely available in the public domain; research that involves anonymised

[8] https://ethics.grad.ucl.ac.uk/

[9] https://ethics.grad.ucl.ac.uk/

[10] https://ethics.grad.ucl.ac.uk/exemptions.php

data in public domain; and studies that are purely observational (non-invasive and non-interactive)". The previous conditions can be a good guideline for the inclusion/exclusion criteria for the online resource to select for the study. In details:

- It is excluded resources that do not give freely access to the information, for example forums and mailing list that do not allow to the searching engines to scan the contents or that require a password or a type of authentication to have access to the information;
- It is excluded resources that explicitly do not allow to use data for research or do not allow data gathering;
- It is excluded data that can help to recognise people, patients or users of the websites; data collected will be stored and analysed in an anonymised way;
- The study is pure observational, user of the selected web resources or platform will not be contacted, and the information in the website will not be altered in any way.

As seen in the Literature Review (chapter 3.6) web resources can offer an unique point of view of the needs of the patients in a different way compared to data collected directly from people via traditional research tools (e.g. interviews, observation and questionnaires). It is difficult to define clear ethical guidelines that are acceptable by all the involved parties. There is not an universally acceptable approach. However, some satisfactory rules can be defined. Golder et al. (2017) explored the participants' opinion to understand what degree of information exploitation is acceptable for them. The authors suggest that every research should consider several aspects when designing the ethics guidelines. Some of these aspects are the type of data analysis (qualitative or aggregate), the nature of the topic (delicate or inconsequential), and other issues like data anonymisation, benefit/risk of the participants, privacy, informed consent design, and confidentiality. These values should be used to address a procedure that has less impact as possible on participants. In particular, Golder et al. (2017) suggest that:

- The use of numeric data (like aggregate statistics) are more acceptable rather than researches that include quotes or elaboration of quotes;
- Terms of service, for example the one used in social media, are often signed without really understand or read all the clauses. It is better do not rely too much on them and to ask directly again to the participants to have access to

the information even this agreement was already given by signing the terms of service;

- Participants have an ambivalent approach to the use of qualitative data in case of data created from a purpose that is different from the research. Some participants do not want that their words are quoted even in case of anonymised data, some others prefer to be quoted to voice their opinion.

After evaluating the previous suggestions, it is considered to add extra protection to the users that created the data for the analysis. It will be used just data freely available online and the data will be anonymised during the research process. Furthermore, direct quotation of the original sources will not be used in the report in order to protect the anonymity of the user. In facts, direct quotation can easily be copied and searched on any searching engine and the original source can be easily identified in this way. This possibility reduces the protection of the user and therefore the respect of the research ethics. The report of a thematic analysis requires the use of quotes to describe the themes. In this case the original sentences are paraphrased.

4.2.3 Materials

Rather than to select a wide range of resources, this study will focus on a limited selection of sources, one for prostate cancer and one for bowel-related cancers. This is an approach that helps to be sure that sources respect both UCL Ethic rules and more extended ethics in order to respect patients' rights.

Source selection criteria

The research keywords "prostate cancer"+"diary"+"stories", and "bowel cancer"+"colorectal cancer"+"diary"+"stories" were researched on google.com. The research was place on June 1st, 2017. The research was conducted in an anonymised Chrome browser page to avoid that personal setting would influence it. It was kept active the geolocation in London (UK) to get a geographic-specific result. The first page results were scanned. It was removed not pertinent contents and advertising-related results. The remained websites that reported a database of patients diaries or opinion are reported here:

Prostate Cancer (PC) sources	**Colorectal cancer (CRC) sources**
community.macmillan.org.uk (Macmillan Cancer Support)	community.macmillan.org.uk (Macmillan Cancer Support)
pcf.org (Prostate Cancer Foundation)	community.beatingbowelcancer.org
csn.cancer.org (American Cancer Society)	csn.cancer.org (American Cancer Society)
cancerforums.net (The Cancer Forum)	cancerforums.net (The Cancer Forum)
healingwell.com (HealingWell)	coloncancersupport.colonclub.com (Colon Talk)
patient.info (Patient)	colonclub.com (Colon Club)
cancercompass.com (Cancer Compass)	coloncancercoalition.org (Colon Cancer Coalition)
community.prostatecanceruk.org (Prostate Cancer UK)	patient.info (Patient)
yananow.org (Yana - You are not alone)	webmd.com (webMD)

It was narrowed the research to two sources, one for Prostate Cancer (PC) and one for Colorectal Cancer (CRC). The selection criteria are:

- Sources must be public and available without the need of registration to access to them;
- Sources cannot be used if websites report explicit declaration of copyrighted material and terms of use that forbid data collection;
- Both of the sources are reported by users of the popular forum acor.org (deBronkart, 2012) as valuable resource websites for prostate cancer and bowel cancer;
- Sources must contain at least +300 diaries of patients that describe their experience with the disease;
- It was use the framework suggested by Katerattanakul & Siau (1999, table 1) to evaluate the sources information quality. Selected sources must show the four qualities presented in the framework:
    - Intrinsic (information has good quality for the use required);
    - Contextual (provide information about the author to verify reliability of the source);
    - Representational (the data is well organized and coherently presented);
    - Accessibility (navigation and selection of the source).

The selected sources are:

1) yananow.org website designed to help people diagnosed as having prostate cancer. The website has an effective and organized selection of information to help patients at their first diagnosis, and extra information is available for people that have been fighting the disease for long time. It is analysed the part of the site that collects diaries of patients[11].
2) coloncancercoalition.org website designed to help people diagnosed as having colon cancer. It is analysed the Survivor Stories blog[12] (stories directly described by the patients and the Faces of Blue blog[13] (a selection of stories written by patients, caregivers, and family members).

This selection method do not guarantee that the selected resources are the best available online, yet the selected sources are enough reliable for the purpose of this research. For convenience, extra elements like images, audio or video embedded in the web pages are considered part of the source. However, links to data to external websites will not be considered for the analysis. Comments of the single stories are included in the analysis. The data is analysed with ATLAS.ti, a popular application for qualitative data analysis. It is not required any particular hardware configuration for the analysis. No particular materials are needed.

4.2.4 Procedure

Samples from the selected sources are collected, saved in static pdf files and imported in ATLAS.it. The analysis follow a traditional thematic analysis approach in three phases (Herring, 2009). The sources are freely coded following a thematic analysis process (Sharp et al., 2007; chapter 8.4). In a second moment patterns and recurring themes are identified by using affinity diagram as method to organise the information (Holtzblatt, 2001; Holtzblatt & Beyer, 2014; p. 24). In the same way of the Study 1, it is followed the approach suggested by Courage & Baxter (2005) Appendix F ("Affinity Diagram" section, p. 744). The last part of the analysis involves a consolidation of the themes, final renaming and descriptions (Blandford et al., 2016; p. 56). The most relevant themes are presented in the Result (chapter 5.2).

11 yananow.org/query_stories.php
12 coloncancercoalition.org/community/stories/survivor-stories/
13 coloncancercoalition.org/community/stories/faces-of-blue/

Data saturation

To understand the point to stop the research it is used a data saturation strategy (Bradley, 2007) combined with a first selection of diaries. Firstly, a list of keywords was produced to find the diaries that probably are going to be more useful for the research. The list was based on the imaging techniques presented by Suetens (2017; p.v-vi and p. 2-4):

List of research keywords for the diary analysis			
CDU CT Contrast Duplex Echography	Image Imaging MRI Magnetic Marker	Nuclear Radiography Resonance Scan Sonography	Tomography Ultrasonography Ultrasound X-ray X-ray

The reduced list is used as primary and more promising selection of diaries for the study. The coding would stop when saturation is reached. It is important to remember that there is not a perfect data saturation methodology, and that more data is not necessarily better than less. Moreover, a saturation point can be influenced by the data collection method, analysis method, and study design. Fusch & Ness (2015) suggest to choose a method that is explicit in the definition of when the saturation is reached. For this specific research it is considered as saturation point when no new code would emerged after the analysis of 10 diaries in a row (the 1% of the total database).

5. Results

5.1 Study 1: The opinion of the experts

The voice of the experts was collected with a series of semi-structured interviews. The transcription of the interviews was used for a thematic analysis. Codes were grouped and the emerging themes were rearranged in an affinity diagram to find the final themes. The collection and analysis methodology is described in chapter 4.1.

5.1.1 Interview collection

The objective was to collect the opinion of at least six experts in this sector. Unfortunately, it was possible to collect the opinion of just four experts: two of them are oncologists who treat prostate cancer; one expert is an oncologist who treats bowel related cancers; and one is a consultant oncologist for the treatment of breast cancer. The last participant does not fit to all the research conditions planned in chapter 4.1 because it was assumed to interview only expert based on prostate and bowel cancer. However, during the research of participants few experts answered to the call, and it was impossible to reach the minimum number required for a comprehensive collection of opinions, so it was accepted to interview the breast cancer expert. The interview contributed with useful information about patients' TDM and general review of the use of medical imaging during a discussion about treatment with the patient. The collected data was compatible with the opinion of the other experts and it was not focusing specifically on breast cancer, so it was included in the analysis.

5.1.2 Main themes overview

This chapter shows the most significant themes emerged from the analysis. Relevant quotes are provided to support each theme. Oncologists say that images are rich of details and too complex to be showed directly to patients ("Medical imaging is too complex"). Furthermore, some patients feel disturbed to see images that show internal parts of their own body and the tumorous mass ("Some patients just do not want to see images"). Some oncologists say that sketching while speaking to patients is often a more useful tool ("Sketching is a powerful tool"), even images are

more powerful in some extreme situation when patients refuse to accept their condition ("Images as hard fact"). Oncologists do not deny the utilities of body scans in treatment decision making with patients, however they underline that the use of medical imaging for TDM is more useful in some circumstances rather than others. For example, medical imaging can be used to inform patients about the therapy ("Images help the treatment"), also the effectiveness of images depends from their nature and the context of use ("Usability depends upon the kind of treatment and image"). Moreover, a cumbersome system is one of the factors that limit the use of medical imaging at present days ("The system is inefficient"). A last important theme emerges from the desires of doctors when they envision the future of cancer treatment: cheap and fast body scans, powerful information systems and virtual meeting between experts and patients ("The medical imaging wishing list"). The following list presents the themes. Themes are reported in details with relevant quotes.

Medical imaging is too complex

The interviewed oncologists stated that the use of medical imaging is often not useful because the visualisation of body images is too complex to be understood by patients: *"I often start with the scan but* [...] *it could* [be] *too much for a patient to understand"* (code 1:4); *"it's hard for me to say how much they* [patients] *really understood"* (code 2:17). Body scans are not equivalent to photographic pictures. They often have distorted proportions and contrast that do not match with reality. They have also many details. An expert can read them but "normal people" can get confused: "*Images have too many details, patients cannot understand what we* [doctors] *are trying to explain"* (code 1:29); *"this one looks quite scary,* [oncologist shows full screen image of a tumorous area] *but actually it measures just 2 cm, it's just magnified, and she* [the patient] *does not know that.* (code 4:27). Oncologists are also worried that to expose patients to body images can increase patients' anxiety: *"for patients* [that] *come here to have radiotherapy* [it] *is quite scary"* (code 1:33). Furthermore, images are complex to be read by oncologists as well. Oncologists have a basic training to understand images but they rely to other experts, like radiologists, for a deep interpretation of body scans. For this reason some oncologists do not feel confident to show directly medical imaging to patients: *"I am*

not a trained radiologist. So I can show some scans but MRI is quite complex" (code 4:8); *"generally I trust to what the radiologist says"* (code 2:2).

Some patients just do not want to see images

A discussion about the treatment decision can be a stressful situation for some patients (as seen in chapter 3.1). Several oncologists reported that some patients prefer do not look at the images of their own body: *"it is like to see too close, like to watch their own body inside. it is quite unique, there are some of them"* (code 1:19); *"it's like when some people have to take the blood and they do not like* [it]*"* (code 1:20) *"patients that want to know as less information as possible, they say: 'Really I do not want to go through this, just tell me what I have to do'. So… each individual has different way to deal with things"* (code 2:15).

Sketching is a powerful tool

Sketching is a common tool used by oncologists to support TDM. Sketching is not universally used: "*Personally, I am not a visual person, so I do not use* [...] *visual* [tools with the patients]" (2:6). However, oncologists that use drawings with the patients say that sketching is useful to explain methodologies to patients: *"I draw a full bladder, an empty bladder and this give a quick reference to the patient to understand why we want to have a full bladder and an empty rectum* [during the treatment]" (code 1:6, Figure 2); *"I use MRI as support and I draw something like this"* (code 1:7). Time is a critical factors because oncologists are busy and they have just few minutes to share with each patient: "*Sketching is very fast:* [medical imaging] *is not helping me, it is not helping her* [the patient] *it is taking time. This is easier* [point at the sketch]" (code 4:31).

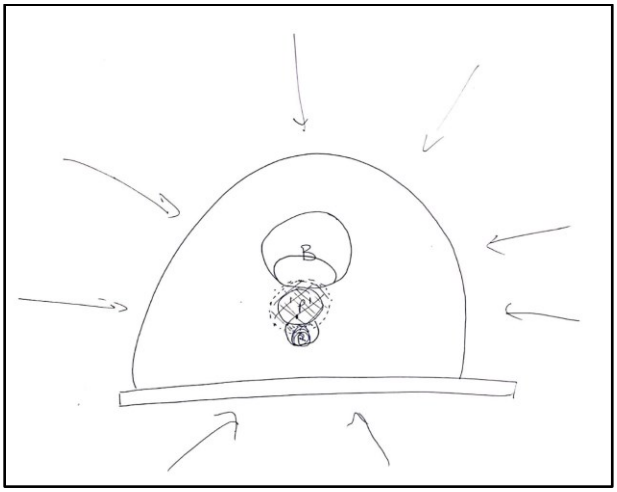


Figure 2: Sketch made by a participant during the interview

Images as "hard fact"

Oncologists consider convenient the use of medical imaging in treatment decision making with patients in some particular cases. For example, an oncologist described the case of a young patient that was diagnosed with cancer at an advanced stage. The patient was refusing to take any therapy, while the opinion of the oncologist was to start a treatment as soon as possible. In that case the oncologist used any tool in their possession to persuade the patient: "[the patient] *did not believe to have cancer. A very big cancer, I was very worried about her. She refused treatment. So in that case I had gone through everything to try to convince her. So* [we] *made exams of everything,* [...] *gone through all the pictures"* (code 4:6).

Images help the treatment

Oncologists showed interest in the use of medical imaging as information support to help patients to understand the treatment process and to prepare patients to treatment. A couple of oncologists brought as example the case of the VERT sessions (Virtual Environment in Radiotherapy). VERT simulates what happen inside a radiology room during the treatment. During the VERT session images of body scans are shown to explain the treatment process to patients: *"VERT session* [patients] *have experience to what is likely they have to expects* [during the

treatment]. *People found this extremely helpful, that's the reason we are looking to improve it"* (code 1:35). This procedure has been successful to show medical imaging to patients and to help them to cope with the treatment process. So far, VERT sessions use general information and anonymised medical imaging. In future it is planned to experiment the same process with personalised sessions that use images from patient's scans: "*in future we will implement personalised scans of the patients during the VERT session"* (code 1:38).

Usability depends upon the kind of treatment and image

Oncologists explained that medical imaging can be useful but just in some conditions. For example, it could be useful in radiology to explain the treatment to the patient: *"I think* [images] *could be useful in surgery or radiotherapy where it is possible to treat a local disease* [...] *to understand anatomy and the relationship between* [body and disease] [...] (code 4:17). On the other hand, medical imaging is less useful in the case of pharmacologic intervention like during chemotherapy: "*So, it is really about understanding the anatomy when the operation will be, while the chemotherapy is not really like that"* (code 4:15). Furthermore, not all the medical imaging techniques are the same. Some are easy to be read by patients without special training. It is the case of PET, that shows the most active tissues with a glowing light within the body: *"In the PET scan is very easy to see where is the disease because it glows very brightly* (code 3:4). Other tomography techniques, like MRI, can be useful at some level of degree. However, some other technologies, like ultrasounds, are difficult to be read without training: *"Ultrasounds you… you have to look at it* [when it is performed], *it is in 3D so unlike you do not look at the video, you cannot accurately measure, so it is not something you can look later"* (4:21).

The system is inefficient

A main key factor for oncologists is the lack of time. Oncologists can share a limited time with the patient, and during that time they have to review the result of the medical analysis, explain the situation to the patient and discuss with them the further treatment decision. During that time is almost impossible to show medical images to the patients because the digital files that contain the medical imaging require too much time to be downloaded and processes: "*Now we have a number of systems to open... and another system to open to show the content* [to the patients]

and it takes time and it makes difficult with the technology that we have available (code 1:24); "*I usually do not have the time to go through all the images*" (code 4:7); "*One of the problems is that to look through the scan is taking too long*" (code 4:18). Furthermore, the computer used in oncologist's visiting room generally lacks in hardware necessary for a complete visualisation of the images. For examples, an oncologist explained that it is possible to show medical images to the patient in a meeting with the radiologist in the radiotherapy department because there is the opportune hardware to show images there (e.g. big screens, fast computers, etc.), while the same is not possible in the office of the oncologist: *"all the images packed in my computer are not good to be seen like in the radiologist room" (code 4:10)*; *"with the radiologist* [...] *when we plan a therapy so we need a lot of support"* (code 3:25). Doctors complain that the system is complicated to use and it is hard to find the required images because patient's file contains a confused mix of analysis reports and examination results without a clear order or the possibility to use a search engine. To find a file the doctor must scan and open one by one all the attachments and that requires too much time: "*I can show it right away. Look here… so I am shutting down my stuff…* [clicking on interface in the PC] […]" (code 4:21); *"I mean it takes* [...] *quite some time. Even this much and they* [the patients] *start to ask questions. So I have to look up and read the report, and maybe…* [the use of images] *is going to take much longer"* (code 4:25). Another problem is that results of the medical imaging analysis are often scattered between different IT systems. Doctors need to open different applications to have access to all the information about the patients: "*Every time* [the] *system takes long time to show images. Where is it? This is a ultrasound,* [...] *this is one picture...* [oncologist is struggling with the mouse to open several windows on the screen of the computer]" (code 4:26); *"It is going to take me all the day! I do not have the time"* (code 4:30). The procedure becomes more complicated when patients get body scan and other examinations from external clinic and hospitals: "[the patient had a] *MRI but she had it at another hospital so I did not have the pictures. A lot of stuff* [exams] *has done externally, so I cannot see that"* (4:20); "*The system is not connected, you do not have access…"* (code 4:21).

The medical imaging wishing list

While speaking about current problems, sometimes doctors envision a future close in time when medical imaging and system would be slighting more efficient than nowadays. In this hypothetical scenario they imagine how treatment decision making with the patient would be better than now. Doctors are imagining that in the future there would be better hardware, more responsive interfaces and faster network based on how the system evolved so far: "*show to people more easily because the quality of information is better, images are better, technology is better"* (code 3:13). Oncologists also forecast that the cost to perform a body scan will decrease so it would be possible to have medical imaging of the patient during the treatment process and not only at the beginning and the end of the treatment. This could let doctors to adjust the treatment session by session and have targeted, personalised, and efficient treatments: "*perform the treatment and to check the accuracy for example by doing CT* [computer tomography] *during the treatment, looking at them, it does not necessarily impact* [directly] *patients* [patients' treatment] *but it impacts the interaction with patients"* (code 3:18). One doctor images a future when is possible to have meeting with radiologists and patients in a "virtual room". By sharing an electronic whiteboard, for example, radiologist and oncologist can manipulate images in the same time, write, and take notes even when the attendees at the meeting are in different locations around the world. This could save a gargantuan quantity of time and get in touch experts from different cities and nations: "*Matrix with different panels, images come here and if we have a plan, if we can arrange a CT scan* [...] *the radiologist could be sitting next to you, or be in China, be in America, drawing around, and potentially drives radiotherapy more accurately*" (code 3:26). This theme is important because speaking about the future shows in an indirect way what oncologists consider not functional nowadays. This theme shows what doctors would like to have now but that is not possible nowadays: powerful systems, possibility to have multiple body scans during the treatment and the possibility to organise meeting with patients and other experts at ease.

To summarise, themes emerged from the thematic analysis exhibit experts' feeling of distrust toward images as manageable tool for treatment decision making. The respondents justified that with the complexity of medical imaging, but in the same time they admit that doctors use images with patients in case of complex TDM

processes. Images are undoubtedly difficult to be used with patients, however the main factors that limit the use of medical imaging are the time required and the hardware necessary to have access to this kind of information.

5.2 Study 2: The opinion of the patients

Thoughts of patients were collected from a series of public diaries available on the Internet. In these diaries, patients affected by prostate (PC) and bowel cancer (also known as colorectal cancer, CRC) describe their experience to live with the disease. Data collection and analysis methodology is described in chapter 4.2.

5.2.1 Collection of the diaries

Data from yananow.org was collected on June 28th, 2017. A total of 786 diaries were collected. Data from coloncancercoalition.org was collected on June 30th, 2017. A total of 359 diaries were collected. The total number of diaries for the analysis are 1145.

5.2.2 First analysis of the diaries with keywords

It was selected a list of words to search inside the diaries. Only diaries that contained at least one of these words were selected for further analysis. It was assumed that the authors of the diaries didn't misspelled the researched keywords. The research was case insensitive.

List of relevant diaries found based on the keywords:

5	CDU	30	Image	25	Nuclear	2	Tomography
267	CT	38	Imaging	0	Radiography	0	Ultrasonography
29	Contrast	238	MRI	1	Resonance	108	Ultrasound
1	Duplex	0	Magnetic	421	Scan	12	X-ray
0	Echography	20	Marker	0	Sonography	11	X-ray

Total diaries that match at least one keyword: 586
PC patient's diaries: 454
CRC patient's diaries: 132

From 1145 diaries the research was narrowed to 586 documents. The selected diaries were used for the further thematic analysis. PC patient's diaries outnumbered CRC patient's diaries four to one. For this reason the order of the two different categories of diaries were interleaved during the analysis. It was proceed in this way: firstly, the diaries were arranged by following the original database input order

(chronological order of the publication of the diaries). In this way it was possible to obtain two lists of diaries, one for every source. Then, 75 of the CRC patient's diaries were ordered as first source for the analysis. This number was chosen because it is approximately half of the total number of the collected CRC patient's diaries. Then, the analysis would continue with PC diaries and the remaining CRC diaries. Therefore, the final arrangement was half CRC diaries, all PC diaries, and remaining half of the CRC diaries. Once organized in this way, diaries were coded one after the other, until reaching the saturation point as planned in chapter 4.2.5. In this way it was possible to have a higher variety of diaries and avoid to reach the saturation point after analysing only one category of diary.

5.2.3 Data saturation and first coding analysis

Data saturation as defined in chapter 4.2.5 was reached after the coding of 352 diaries, which 277 of them are PC patient's diaries and 75 CRC patient's diaries (after the 267th diary no new codes were created). The analysis created a total of 144 codes. Some of them were merged together in 6 code groups due topic similarity or redundancy of same topic with different codes. This led to an initial 21 preliminary themes with a rudimentary description. A further refinement of the information via affinity diagram guided to the following final themes.

5.2.4 Main themes overview

This chapter reports the main themes identified during the analysis. A paraphrased sentence describes the original diary quote. This approach is needed in order to protect the privacy of the author of the diary (as seen in chapter 4.2.2). Overall, little information is present in the diaries about the use of images in treatment decision making. Some themes that emerged from the analysis suggest that probably images are not important for the patients per se. Patients' tendency is to trust to experts' analysis of the images and to use that information for further decisions. However, it is not clear if this approach is due to patients' difficulty to interpret the images or just because images are not usually shown to patients or not presented in an understandable way. Some themes suggest the first hypothesis, because to understand their medical condition is an arduous journey for patients ("Information overload", in chapter 5.2.5). However, the analysis of the opinion of the experts

(chapter 5.1) demonstrates that oncologists often prefer to do not show the images to the patients. The situation is analogous to the chicken-and-egg dilemma. At any rate, there is too little information about this topic to withdraw clear conclusion (refer to chapter 6, Conclusions, for a detailed review of the whole research).

5.2.5 Main themes presentation

Several themes emerged from the final thematic analysis of patient's diaries. The research topic that guides this analysis is the usefulness of medical imaging in patient's treatment decision making. Main themes on this topic show that patients do not have high interested to look at the images by themselves. They are more interested in the meaning of the images, and they trust on experts' opinion (oncologists and radiologists) for the interpretation of body scans and other visual analysis ("Images are for expert"). Other important sources of information is the previous experience of patients ("In pursuit of previous experience") and the opinion of several experts ("The more doctors, the merrier patients"). The research for information about their condition can be extremely exhausting and some patients can develop frustration about the complexity of disease outcome and treatment options ("Information overload"). Furthermore, the literature review presents a contrast with the collected data. For example, while the initial information suggested a possible link between bowel and prostate cancer (chapter 3.1), the thematic analysis showed some differences between how patients perceive these two diseases ("TDM keywords: PC/CRC differences"). Other important themes emerged from the analysis that are not directly connected to the principal intent of the research. However, their emersion ("Spouse support in decision making") confirm some information collected during the literature review (chapter 3.5), and their presence increase the reliability of the sources of the diaries. It is also noticeable that the moment of the discovery of the disease is one of the most common experiences shared in the diaries ("The dramatic memory of the discovery"). It is also the one described more in details by patients with vivid and dramatic details. It is unquestionable that this is one of the key moments in the experience of patients with the disease, and one of the moments when medical images and other forms of support should be implemented to improve the quality of the treatment journey of the patients.

Themes are presented in the following part of this chapter, and they are divided in

two subgroups: the ones related to the research question and other important emerging themes not directly related to the research question. Exemplificative quotes are paraphrased text from the original diaries.

Themes related to the research question:

Images are for expert

Patients do not show particular interest to read body scans and other medical imaging by themselves. Patients are mainly interested to images' meaning given by the expert. Only in few cases patients describe how they perceive the images. For example, a patient shared his experience with the brachytherapy intervention. The brachytherapy intervention is performed by introducing small capsules (seeds) that contain a radioactive substance: *the doctor uses a CT scan (a computed tomography scan that uses X-rays) to place the seeds [...] my CT scan looks like two car headlights approaching at night* (code 329:1).

In pursuit of previous experience

Despite the understanding that each case of cancer is unique, in many diaries patients express the need to gather information from other patients with similar conditions rather than to focus too much in expert's initial diagnosis. Patients focus on experiences, decisions and outcome of therapies: *I spoke to a dozen guys, collecting information on their conditions before and after the treatment. I was convinced that *** could be the best therapy for me, even through my doctors disagree* (code 1:5*).*

The more doctors, the merrier patients

In many diaries is particularly stressed the need to listen the opinion of different experts. Sometimes this is necessary because the medical field is so complex that many experts are necessary to identify a disease, plan a treatment and to verify it: *I also consulted a radiation oncologist who told me I needed [...] treatment right away. He made me an appointment with a medical oncologist [...]* (code 326:1). However, generally the opinion of the patients is related to the fact that it is important to have consultation from different doctors and be completely informed of all the options

before to start a therapy. This is evident with prostate cancer (PC), a disease that have different options without an optimal treatment choice.

Information overload

Especially in the case of prostate cancer, patients start to collect more information about their disease in order to make an informed and rational treatment decision*: I have spent more than two months researching for treatment options* (code 3:1). However they soon collide with complex information. PC is a disease that has not clear development progress (as seen in chapter 3.1). Frustration often rises from this situation: *I have researched every treatment I can find including experimental clinical trials. I change direction every time a new information reveals itself* (code 86:2). *After the diagnosis I have read books, visited websites, and realised that I can easily become overloaded with information* (code 86:1).

TDM keywords: PC/CRC differences

A clear different pattern emerges from patients affected by prostate cancer (PC) compared to the one affected by colorectal cancer (CRC). In the case of PC, patients' description of their conditions often is strongly related to their value of PSA (Prostate-Specific Antigen, an antigenic enzyme released by the prostate that is generally found in high concentrations in the blood of men with prostate cancer). In some case some entry diaries are just a sequence of PSA values, e.g. *Nov. 1994....PSA was [...] March 1998...PSA was [...] ng/ml May 1999.....PSA was [...]* (code 128:14). In case of bowel cancer the diaries are much more distinct, and the most common topic that emerges from the diaries is a first diagnosis due the discovery of blood on the stool or other bowel problems. These first symptoms lead to a diagnosis via colonoscopy: *[...] woke up with bathroom issues to the point [...] needed to go to the hospital* (code 889:1); *went in for a colonoscopy and was later told that [...] a tumor* (code 953:1). However, cases of accidental discovery of the disease during routine examinations are common: wh*en I went in for my first ever-routine colonoscopy* [...] (code 947:1); *I was 50 and I was going to have my baseline colonoscopy* (code 902:1).

Themes not related to the research question:

Spouse support in decision making

Spouse's opinion is important and is taken in consideration in TDM in the case of PC as seen in chapter 3.5: *my wife and I decided that [...]* (code 10:1). A negative development of the disease leaves the patient with a poor quality of life and a major concern is that the burden for the spouse is too intense. The most representative case is the diary of a patient with a negative outcome of the disease (ID 182). The wife took care of him in many ways, for example looking information about experimental medication: *My wife [...] checked *** out online and found the cost to be [...] I was not optimistic about these capsules [...] but my wife suggested that we try it* (code 182:15). She also took care about his husband's mental care by keeping him busy with several activities when the disease progressed so much that working was not an option anymore: *I'm playing golf [...] and do anything else my wife finds for me to do* (code 128:16). At the end, the cancer developed metastasis to the spinal cord: *I'm not able to walk anymore. It makes me question whether I want to extend my life with chemo* (code 182:12). Patient's last words are about concern to be a burden to his wife: *I am wearing out my wife* (code 128:13).

The dramatic memory of the discovery

Most diaries present in extreme details the moment when patients received a positive diagnoses of cancer: *One evening we had ordered take-out; after I had extreme cramping, my husband took me to the emergency room* [...] (code 962:1). For example, another patient recall in details his golf match when he received "the call": *It was a mild breezy spring day [...] I had just hit a tee shot down [...] which made a fortunate bounce into the fairway, leaving me a short iron from the green. However, before making that short iron shot I received a call I from the doctor. He said "report confirms you have cancer" (code 969:4).* This turn of events is extremely dramatic and stressful for the majority of patients: *In an instant my world changed. We made an appointment for the biopsy [...] I drove home. I cried like a baby* (code 11:2).

To summarise, diaries present little information about patient's opinion toward medical imaging. Patients would like to learn and understand more about their

condition but the very complex development of the disease is a great obstacle. Furthermore, some minor differences emerged from patients affected by prostate and bowel cancer.

6. Discussion

The purpose of this dissertation is to investigate the use of medical imaging in treatment decision making in case of prostate and bowel cancer. This was completed by analysing both the opinion of oncologists and patients in order to have a complete overview of the problem. The main finding of this research is that currently medical imaging is not a tool commonly used during treatment decision making when patients are involved in the process. Information collected from patients and experts underlines this fact (chapters 5.1.2 and 5.2.5). Nevertheless, medical imaging has the potential to be useful to help patients during treatment decision making. For example, possible evidences of this theory are the use of medical imaging during the VERT session in radiotherapy, and the TDM process with difficult patients that involve the use of medical imaging (chapter 5.1.2). The rare use of imaging roots in the elaborate process that is generally necessary to have access these documents with the current systems. Images are difficult to retrieve due poor organization of medical databases, also the current hardware cannot visualise the images in a proper way. Time is a crucial aspect during the meeting sessions between patient and oncologist, and expert prefer faster and more economical way to support the conversation. Insight collected from the research is consistent with the importance of communication between patient and doctor. In particular, the study of the opinion of the patient is compatible with evidences collected during the literature review, for example the difficult approach to treatment decision making (TDM) for patients affected by prostate cancer (PC, chapter 3.2). More important, the result of the research shows an ambivalent nature of the use of medical imaging in TDM. Patients do not consider images as crucial tool during the decision process. Doctors think that images are too complex to be read by patients and cumbersome to use. However, medical imaging was reported as a key factor during the training of patients for radiotherapy (VERT sessions) and to discuss with patients about difficult treatment decisions (chapter 5.1.2). Unfortunately, the research studies were affected by a series of obstacles. In the first study (the opinion of the experts) the collection of data found insurmountable problems for the recruiting of participants, and the time that each participant could share for the research was scarce. Nevertheless, the semi-structured interviews offered a valuable quantity of information, and participants contributed with enthusiasm to the

research. In the second study (the opinion of the patients) there was abundance of sources, however the diaries did not offered much specific information about the research question. Furthermore, the design of both studies has a number of possible limitations. The planned interview to experts had to deal with the short time that participants had to offer. It was not possible to ask many side questions that could enrich the final findings. In the case of the opinion of the patients, the analysis of the diaries showed little interest of the patients to share their opinion in TDM. This result could be a resource problem, for example the chosen source could be not the best one for this analysis. Another possible reason could be a problem with the chosen medium (diaries), maybe different media could be more effective sources. Further research should be undergo to clarify it. For future research is suggested to do not follow the same methodology. A possible alternative is to include a pilot research with samples from different online sources to find the most promising data source. Although this study was conducted with a limited sample, the results can be partially generalisable for TDM between doctors and patients. In particular, the diaries study showed that there are a couple of moments in the treatment process when medical imaging assumes a vital importance for patients. These moments are when the cancer is detected for the first time and after the treatment. In the first case, the medical imaging is the proof that confirm the illness, in the second case images confirm the success or the failure of the treatment. These moments are strongly carved in the memory of patients. Patients spent long paragraphs to describe that in the diaries, with many details. It is noticeable that these two stages of the patient's journey through the disease are two key moments for the use of medical imaging, and that further research should focus here before to study potential intervention in the use of medical imaging in TDM. In conclusion, this research shows that images are complex to be read and probably they would never become a main tool in TDM, however their could offer a higher support in the communication between patients and doctors.

7. Conclusion

This research focus on patient's treatment decision making (TDM) in case of prostate and bowel cancer. In particular, the research seeks the degree of usefulness of medical imaging (chapter 2). The literature review presented a brief research of the main findings on related topics (chapter 3). The research was planned with two studies to be able to collect both the opinion of doctors and patients (chapter 4). The results showed that medical imaging can be useful in this context, but imaging is underused due images reading complexity and technical difficulty to retrieve image files from the current systems used in health care (chapters 4 and 5). During the next years technology will probably progress, and more powerful and economical electronic systems will be available. In this prospective scenario medical imaging could offer more support to both patients and doctors in treatment decision making. However, another key factor is the design of the interface systems. Contemporary tools are too cumbersome to be used, and they limit the usability of medical imaging during the doctor-patient meetings. New systems must be designed with the ability to storage and retrieve medical imaging in a faster way. Images preview and smart research tools should be implemented as well. However, this research has several limitation that prevent to draw conclusive findings. The recruitment process to find participants among the expert was more difficult than expected (Study 1, chapter 5.1). In a similar way, useful information from patient's diaries was sparse and difficult to collect (Study 2, chapter 5.2). Therefore, it is hard to support strong final recommendations. Nevertheless, it is most likely that medical imaging has an hidden potential, and more research on this topic can disclose it. For future research it is suggested to plan more carefully the design of the study by allowing extra time for the recruitment process of doctors and other medical personnel. It is also suggested to avoid the research of information about TDM via patient's diaries. Diaries are an useful resource of many information about patients but probably they are not the most efficient source for this specific kind of research. In conclusion, present-day medical imaging is just a minor tool used by oncologists to communicate with patients during the delicate stage of treatment decision making. In spite of that, the use of medical imaging has strong potential to become a powerful resource for treatment decision making in case of prostate and bowel cancer.

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9. Appendix

The following documents are included to extend the understanding of the research. They are composed of: the semi-structured interview plan used to interview oncologists (chapter 9.1); the information sheet shared to the participant to inform them about their rights (chapter 9.2); the transcript on one of the interviews of Study 1 (chapter 9.3); an example of one of the sketches created by the participants during the interviews (chapter 9.4); the affinity diagrams generated during the thematic analysis of both studies (chapters 9.5 and 9.6); and the project plan of the dissertation project (chapter 9.7).

9.1 Study 1 – Semi-structured Interview Plan

Planned themes/ questions for semi-structured interview

Oncologists

Before interview check:

- Have copies of information consent
- Have pens, notebooks to take notes
- Check that recording tools work, batteries are full, etc.
- Post it, paper, tape

1. Opening the conversation (put participants at ease) 1min
    a. Thank them for time they share
    b. Explain their expertise is precious and want to know their opinion
    c. Tell interview will take 20-30 min but they can interrupt any time - if less time available try to reduce intro part and focus directly on main questions

2. Introducing the research 1min
    a. Explain purpose of the research: collect data about treatment decision making with patients, understand how they deal with patients in this context, collect info about which visual support can be used in TDM and how
    b. Show documents information consent, explain details, explain which data are collected and how, make sign information consent, leave a copy

3. Beginning the interview [warm up] 1min
    a. Ask some background data: specialization, how many years working with patients

4. During the interview 15min
    a. Introduce main purpose of interview: have their opinion about how patient deal with TDM, focusing on medical imaging
    b. Could be medical imaging be useful to help patients in treatment decision making?
    c. If not, why? What is missing in imaging to be useful? / Which characteristics should it have to be useful? / How imaging should evolve to be useful to you in TDM with the patient?
    d. If possible make specific examples with something that really happened with patients

    {if extra time}
    e. Ask if possible to have a copy or take a picture of the visual support material if used (assure data taken in anonymised way, e.g. use crop/ post it or paper to mask identifying information)

5. Closing the interview 5min **(* ask these question only if time is available)**
    a. *There something else on this topic that you would say?
    b. *There are closer related topics that I did not mentions?
    c. *There are something on previous questions that you forgot to tell me?
        i. (this happen often after record off - people feel more relaxed)
    d. Thank for time/info provided (1min)
        i. Explain how info will be used now
        ii. Explain hope info will be used to understand better experience patients and improve the quality of experience in future for both patients and doctors
        iii. Can introduce to other doctors? (snowball recruitment effect)
        iv. Offer small present to thank for the participation (e.g. quality coffee or tea in gift wrap).

9.2 Study 1 – Information Sheet for Participants in Research

UCL DIVISION OF

Information Sheet for Participants in Research Studies

You will be given a copy of this information sheet.

Title of Project: **Improve patient's treatment decision making process in case of prostate and bowel cancer**

This study has been approved by UCLIC Research Department's Ethics Chair [Project ID No]: UCLIC/1213/015/Staff Blandford

Name, Address and Contact Details of Investigators:

Principal investigator:
Professor Ann Blandford
UCL Gower Street
London WC1E 6BT
United Kingdom
+44 (0)20 3108 7049

We would like to invite you to participate in this MSc thesis project overseen by researchers at UCL. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

We are aiming support patients' treatment decision making in case of prostate and bowel cancer. As part of that, we would like to collect the opinion of experts like oncologist and treatment technicians who have experience of working directly with patients. We are interested to collect your experience with patients; your opinion about what difficulties patients experience, needs and desires about the therapy choice and progress. You will not be asked personally sensitive information or patient's personally sensitive information, and can refuse to answer any questions that you do not wish to.

All data will be handled according to the Data Protection Act 1998 and will be kept anonymous. Only the student developing the UCL MSc thesis, Ilario Toniello, and the advisor professor, Professor Ann Blandford, will have access to your anonymised data. With your permission, anonymised quotations from your interview may be used in reports about the study.

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

UCL DIVISION OF

Informed Consent Form for Participants in Research Studies

(This form is to be completed independently by the participant after reading the Information Sheet and/or having listened to an explanation about the research.)

Title of Project: **Improve patient's treatment decision making process in case of prostate and bowel cancer**

This study has been approved by UCLIC Research Department's Ethics Chair
[Project ID No]: UCLIC/1213/015/Staff Blandford

[redacted]

I ……
agree that I have

- read the information sheet;
- had the opportunity to ask questions and discuss the study;
- received satisfactory answers to all my questions or have been advised of an individual to contact for answers to pertinent questions about the research and my rights as a participant and whom to contact if I have any concerns.
- I understand that my participation will be audio recorded and I am aware of and consent to the analysis of the recordings.
- I understand that the researcher could ask to take pictures (photographs) of artifacts involved in the research. The researcher will ask before taking pictures and the participant can refuse the request without need to explain the reasons.

I understand that I am free to withdraw from the study without penalty if I so wish. I understand that I consent to the processing of my personal information for the purposes of this study only. I understand that any such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Signed: **Date:**

[redacted]

I, ILARIO TONIELLO
confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable).

Signed: **Date:**

9.3 Study 1 – Transcript of One Interview

The following transcript of one interview is included as sample of the collected data from the opinion of the experts.

{!mediafile Interview Participant 1.m4a}{!name "Interview participant 1.rtf"}

{_time}61.02{/_time}based on your experience, I would like to understand if medical imaging could be useful for patient during the treatment decision making process. do you use imaging with patients or not? do you use other visual aids to explain to the patients? A mix of both?

{_time}122.75{/_time} I tend to use a combination of both. When I meet the patients to discuss about the treatment options, first of all I establish what they understand by the diagnosis and during that time we go through the imaging that they already have done for the diagnosis. For prostate cancer they have a MRI scan and a bone scan. Some patients says they do not want to look at their scans, I go through the images and explain where the disease is (170) and I would use together with a diagram that I draw down to the patient. I explain and talk through the radiotherapy options. I tend to use a combination of both.

{_time}194.03{/_time}. so a combination of both…

{_time}199.92{/_time} I often start with the scan but often the scan is too much or it could too much for a patient to understand so I do this diagram for the patient to understand. So it it the most to describe… for example, patient would come with the bladder full for the radiotherapy, so I draw the patient's bradder, the portion of bladder, why it's important for the bladder to be full. I draw a full bladder, an empty bladder and this give a quick reference to the patient to understand why we want to have a full bladder and an empty rectum

{_time}244.64{/_time} do you draw a map of the body? of the intervention? may I ask you to draw it to me now?

{_time}258.14{/_time}I use MRI as support and I draw something like this [drawing see reference picture] and I also I use a picture, a diagrammatic picture to show it and here - images from the VERT session, generally they are people that have already done the VERT session

{_time}287.66{/_time}something that you propose to patients?

{_time}292.44{/_time} after they have to go through the radiation session, so I show them what they have to go through. I draw here what I usually do
so… it depends what we are going to treat, {_time}350.31{/_time} so I make a very simple diagram that mimic che scan of the MRI so I explain to them, this is a picture of them, lying on the table, the head is here, and the feet are here, and this picture is cut away through. and this is the body… this is the bladder… this is the prostate… and this is the bowel. so the prostate lies just behind the bladder… this is the beam of the radiation. we use arch beam , this is a representation of the beams or the radiation, when we shake the beams they treat the prostate around them and the margin around them and adjust around movement. we also in patients with image guards we perform a radiotherapy we have three gold grain seed planted around the prostate that are used to line up with the x-rays when doing the treatment or in alternately we have a scan each day and we use it to line up instead. {_time}441.49{/_time} so this lined area is the treatment target area and, for example, if the bladder is nice and full, this is a small area, this is the proportion of the bladder that is affected by the treatment - if the bladder is empty this proportion of the bladder is much higher, much larger of the whole bladder with the same area. in this way the patient can quickly visualise why it's important to have a full bladder and I can also explain how the treatment is performed and explain that they have to drink a bottle of water 20 minutes before to perform the radiotherapy each day when they have to go through this approach. also in the same way, if the bowel is full of gas or motions it can push up

the prostate, it can actually push out of the target position so the amount of radiation that goes off the treatment area become more important. For this reason we also want that the patient has an empty bowel before to take the radiotherapy each day. we do it buy assist them through the diet, we give them a meaningful diet so there's less gas in the bowel. We also ask them to make some exercises to empty the gas from the bowel on the treatment day in the way to have the bowel as empty as possible. so I use this diagram, I also use the scans, but try to discuss about how and why is important to have a empty bowel and a full bladder by using a MRI scan is more difficult to use a simple diagram and an explanation

{_time}549.52{/_time}so you use both…

{_time}550.63{/_time}I use both

{_time}640.43{/_time}in your opinion, how medical imaging could help better patients to understand better their conditions and help them to decide the best therapy?

{_time}659.53{/_time} when we go through the imaging they have to understand where is the prostate in relation with bowel/bladder and the size of the side effect, for example, so we are able to go through this – but of course we have a range , a spectrum of patients some patients, quite elderly, they find the thing more difficult to process in the sense of the technology compared to young patients so we need to be able to accommodate all the individuals, about all the patients needs, and some people do not want to see their own scans, they do not want to get so direct, so something of more generic would be more useful for them

{_time}708.70{/_time}why in your opinion these patients don't want to see the scans?

{_time}710.36{/_time}well, everyone is different. well for some of them it is like to see too close, like to watch their own body inside. it is quite unique, there are some of them. it's like when some people have to take the blood and they do not like to see their blood to have taken. so there are several reason. as doctor we need to be able to accommodate for all the needs.

{_time}751.46{/_time} do you think that sketching is more effective?

{_time}777.77{/_time} some patients need more details compared to others. need to create contents for all. also the clinic get more pressure over time, so we must create a sort of interface that it is easy to access. for example now we have a number of system to open and another system to open to show the content [to the patients] and it takes time and it makes difficult with the technology that we have available. for example we hvae to open one to have access to the images, to one system to have access to patient's records and patient's result another system to cooperate and make it accessible/useful in clinics (GPs) does it make sense? we have several system and when many systems are active in the same time it slow down a lot the computer… whatever it is it must work with your time

{_time}861.85{/_time} is a problem the fact that these systems should be integrated?

{_time}868.34{/_time} I think the fact that the way it is used it is supposed to be easily accessible and it could be complicated to add a new system or to change to a different one respect the one used in this clinic. it is not possible to spend 10 minutes just have access to all the information needed. it's a problem of a practical, day to day ah, the images have too many details the patients cannot understand what we are trying to explain - pictures make the patients aware, does it make sense? so it is incorporating those aspects. and you saw what we do in the VERT, already, so we show that and make make patients incorporating the planner, a road plan of their therapy

{_time}967.65{/_time}is it something that are you doing right now?

{_time}972.02{/_time}this is something that we are going to to in the future -people will have the possibility to see during their [VERT] session their own scans. We are planning to make the patients come and see the radiographers and the nurses at clinic and see together their road plan

{_time}1007.13{/_time} how do you feel this process is going to affect the patients and their feeling about

radiotherapy?

{_time}1015.32{/_time}I think it is going to be very useful. of course, for patients come here to have radiotherapy is quite scary. be able to see what is the procedure be able to describe something is not like to have access to the department and have access to the therapy machines themselves, have to accommodate during the VERT session - have experience to what is likely they have to expects. people found this extremely helpful, that's the reason we are looking to improve it

{_time}1087.70{/_time} feedback from patient. very supportive. also when patients come for treatment the patients come for treatment we do bladder scan to check if bladder is full for prostate treatment. we use as record so the patient know that we check the bladder each day and that the target they know

{_time}1118.96{/_time} do you show it to the patient, like an image?

{_time}1124.88{/_time}no the scanner gives a number that show how full is the bladder so we can tell them if they prepared for the

{_time}1131.90{/_time}so, do you discuss this value with the patient?

{_time}1133.25{/_time}yes, we tell where we are,

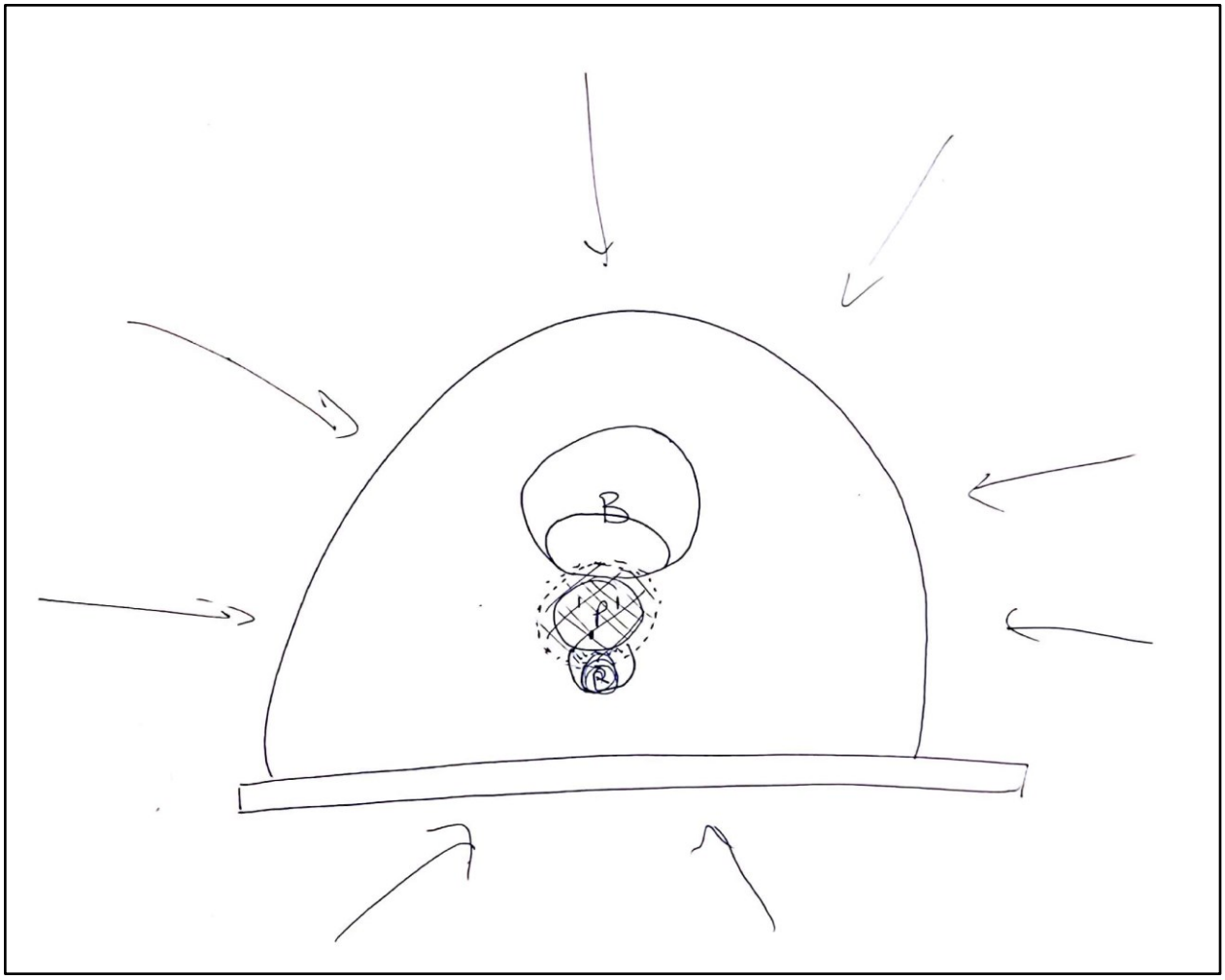
{_time}1164.34{/_time}it's everything I wished to ask you. There something extra that I did not ask you about this topic and maybe popped up in your mind?

{_time}1171.53{/_time}I think I said everything about it. maybe in future we will implement personalised scans of the patients during the VERT session

{_time}1194.26{/_time}thank you very much your your help… [etc. exchange courtesies to end conversation]

9.4 Study 1 – Example of One Sketch

This is one of the sketches produced by the participants during the interview to explain how sketches are used during the treatment explanation process. The images was made by the same participant of the example interview presented in chapter 9.3. The image is also the same referred in the related quotes in chapter 5.1.2.



Notes post interview about the meaning of the image:

- The image mimic a tomography of the body of the patients.
- The oncologist keeps the image vertical in front of the patient and explain that it represents a “slice” of patient’s body, with the rectangle as the board where the patient lies, the arc is the shape of the body, and the arrows the directions where the radiation beam comes from to treat the prostate. The radiation beams move constantly around the body in the way to focus its power just in the internal tiny area of the prostate.
- The three circumferences in the middle of the image are the three organs that affect the treatment. The one marked with a B is the bladder, P is the prostate, R is the rectum.
- The sketched model is realized to make the patient understand why is important that the bladder is full and the rectum is empty for a correct treatment session. The oncologist draws the area affected by the treatment (the middle dashed circle line) and it shows how the condition of a full rectum

and an empty bladder makes the treatment difficult and expose. In this condition an excessive portion of healthy tissue is targeted by the radiation beam. The oncologist draw the opposite situation and they shows how this configuration of the organs is optimal for the treatment. The oncologist draw the images, one over the other, so it is possible to see the double circles in the images near the letter B and R that represent the two conditions. This has much more sense while the oncologist draw it in the front of the patient because images are produced one by one during the explanation.

9.5 Study 1 – Affinity diagram

9.6 Study 2 – Affinity diagram

9.7 Project Plan

EIT Digital Master Course – Human Computer Interaction Programme

Entry: Aalto University (Helsinki, Finland)
Thesis Supervisor: Prof Marko Nieminen
Academic Coordinator: Dr Mika P. Nieminen

Exit: University College London (London, UK)
Thesis Supervisor: Prof Ann Blandford
Academic Coordinator: Dr Chris Evans

Industry partner: Elekta
Industry advisor: Dr David Gilmore

Master thesis project proposal

by Ilario Toniello

August 2017, version 6

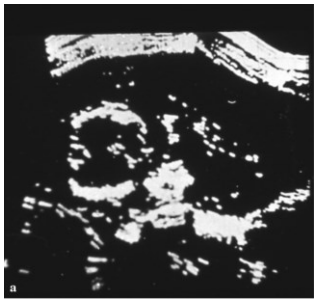
1. Aims

How to support prostate cancer (PC) and bowel cancer (colorectal cancer, CRC) patients' TDM (treatment decision making)? Can communication tools based on future high-res body scan imagery be a good solution?

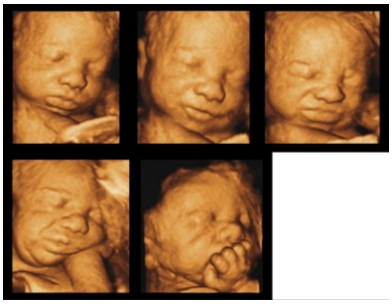
The research started from the collection of information from the web, exit university supervisor, company advisor and an interview with an oncologist.

a) The initial idea

The initial idea started from the comparison between an ultrasound image made with traditional echography and one with the modern "4D ultrasound":



Ultrasound in 1972



Contemporary 4D ultrasound

(Source: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3987368/)

Modern 4D ultrasound systems do not add a lot of extra information compared to traditional imagery. Specialists are able to read and have more information about fetal status from 2D scans and other monitoring techniques (eg. heart beat diagrams) [1]. However, 4D ultrasound systems have been a commercial success and prospective parents pay extra money to have the possibility to catch a glance of the future newborn's features. This happen because 4D ultrasounds scans are easily readable by everyone. These images can create a strong emotional impact on people, especially in prospective parents that are expecting a baby [2], even the possibility of an emotional bond between future parents and the fetus through imagery is still debated [3].

A similar evolution of image resolution has been progressing on body scan imagery, one of the businesses of the partner company Elekta. Nowadays oncologists use several tools to help themselves to communicate with a patient and patient's family in Treatment Decision Making process (TDM). For example, doctors use schematic illustrations or sketching. The use of body scan images is avoided because it is difficult for ordinary people to read them correctly and that can generate further confusion and distress in people that are already facing a difficult situation [4]. However, in future the body scan images will have much higher resolutions. The technologies that are going to disrupt this field are the 3D reconstruction of body from scan [5], identification of organs and important part with a combination of different scanning techniques [6] and augmented reality [7]. Furthermore, illustrators and animation artists are exploring new developing tools that let them to create engaging illustrations and 3D animations of very high quality in a fast and affordable way [8].

b) After the pilot test

The minor thesis research was used as pilot test to collect patient's opinion by online sources. It emerged that it is very difficult to use the Internet as source of information to focus in a very specific topic like imagery in TDM. Web resources demonstrated to be a valuable source to collect user's opinion. It was also hypothesized that Q&A tools like Quora.com could replace the reference system [9]. However, web contents are structured in a very different way compared to traditional sources, and some researchers suggest that the traditional analysis approaches should evolve to consider specific aspects of the Internet [10]. A possible approach for the Master Thesis Project could be to focus on a very

specific topic like imagery and to access directly to patients as participants. This approach is not possible due the ethical and temporal limitations. Consequently, not focus in the specific topic of imagery in TDM when family is involved is not a viable option. The aim was changed to collect general opinion of patients from the web, and collect the opinion of experts directly via interview and qualitative analysis. The purpose is to collect useful information that could help to improve TDM methods. Imagery is still one of the objectives of the research but not the main one.

2. Methods

Which methods can be used to help patients in treatment decision making? Can innovative tools based on imagery be positively accepted by patients? This is a sketched structure of the methods used in the research.

The Thesis Project consist in two different sub-researches

a) The opinion of the expert

Aim: find TDM strategies from the point of view of the experts;
Method of collection: quantitative semi-structured interview;
Participants:
6-12 oncologist, via one2one interviews;
Objective: collect 3-6 hours circa of interview to transcript;
Analysis: thematic analysis of the transcript.

b) The opinion of the patient
Aim: find TDM strategies from the point of view of the patients
Method of collection: online public resources such blog, open forum, and mailing list archives;
Participants: none;
Objective: collect relevant information from several resources, the objective is to try at least two different resources (patients' diaries, mailing list of patients, support forum for spouses and family). It will be used a Theoretical Sampling approach [11, p.25] for the web resources. The limit of the quantity and quality of the resources will be valuated by a cyclical procedure of collection, analysis and evaluation of the findings.

The findings will be summarized and commented with the support of relevant information from a literature review.

3. Limitation of research design due ethics

a) Why do I not involve patients?

Due the strict limitation of ethics rules [12], I cannot involve directly patients in the research, also I cannot collect data directly with interviews or other research methods that involve directly participants that are vulnerable. For the collection of people's opinion I am going to perform a thematic analysis based on the data shared by patients and families in websites and forums created by patients to share information. Recently many patients created online communities where they share information and opinions about diseases, treatments and discuss about life as people fighting cancer [13]. This information is extremely valuable and if opportunely anonymised can be analysed for my research. Of course, there are some assumptions to make before collecting data and some limitation in reliability of the sources but these considerations and limitations will be explained and supported by relevant literature in the thesis.

c) Indirect collection of data from the participants

A final ethical problem is related to the test of the different communication tools. I cannot ask to people to imagine to be directly involved in TDM, it could cause distress and it would not respect ethical principles and standards [11]. For this reason I want to use an indirect way to collect data. By using personas and scenarios I want to create stories about how fictional characters use different TDM tools and I will use some standard methods to collect participants' opinion about the preferred methods. Details about the research method will be defined later during the developing of the thesis and it is my will to try to use as much as possible standard methods that have been tested and validated before in previous researches.

4. Focus in a specific form of cancer

Cancer is a word that is used to describe a wide range of diseases, often extremely diverse between them. Involved experts and treatment possibilities can vary, and the complexity and variety of the topic is elephantine. For this reason I decided to focus in one of the most common form of cancer to concentrate the research of information in a controllable segment. I decided to focus on prostate cancer for several reasons:

- It is one of the most common forms of cancer [14];
- Like many form of cancer it is related to people in advanced age so the involvement of family and significant other in TDM is common [15];
- The industry partner Elekta makes and sells machines for the treatment of this disease, so the company can actively help in the research;
- There are barriers in communication between prostate cancer patients, doctors and families due the particular nature of the disease. This disease can create a strong psychosocial impact in patients' lives and relationships due the hegemonic masculinity constraints in Western cultures [15]. The identification of communication tools that can help TDM for this form of cancer is an urgent matter compared to other diseases where the doctor-patient communication is easier.
- Bowel cancer (colorectal cancer, CRC) is a different disease, but there are some similarities between PC and CRC. For example, some similar points are the side effect of the treatments, the treatment of mobile, soft tissues in the same area of the body, and the impact that the disease can have on the life of patients. Furthermore, CRC it is a disease that impact both male and female and this reason can help wide the research to both genders.

5. Thesis structure

under development

- Title
- 1. Abstract
- 2. Introduction
    - 2.1 The research question
- 3. Literature review
    - 3.1 The reason to focus on prostate and bowel cancer
    - 3.2 The bond between patient and doctor
    - 3.3 Why patient's opinion matter
    - 3.4 The new role of patients in TDM
    - 3.5 The e-Patient new era
    - 3.6 Masculinity and spouse's special role in prostate cancer TDM
    - 3.7 The web as opinion source [+ add extra review]
- 4. Methods
    - 4.1 Study 1: The opinion of the expert
        - 4.1.1 Two different opinion collection settings
        - 4.1.2 Oncologists
            - 4.1.2.1 Participants' details and inclusion/exclusion criteria

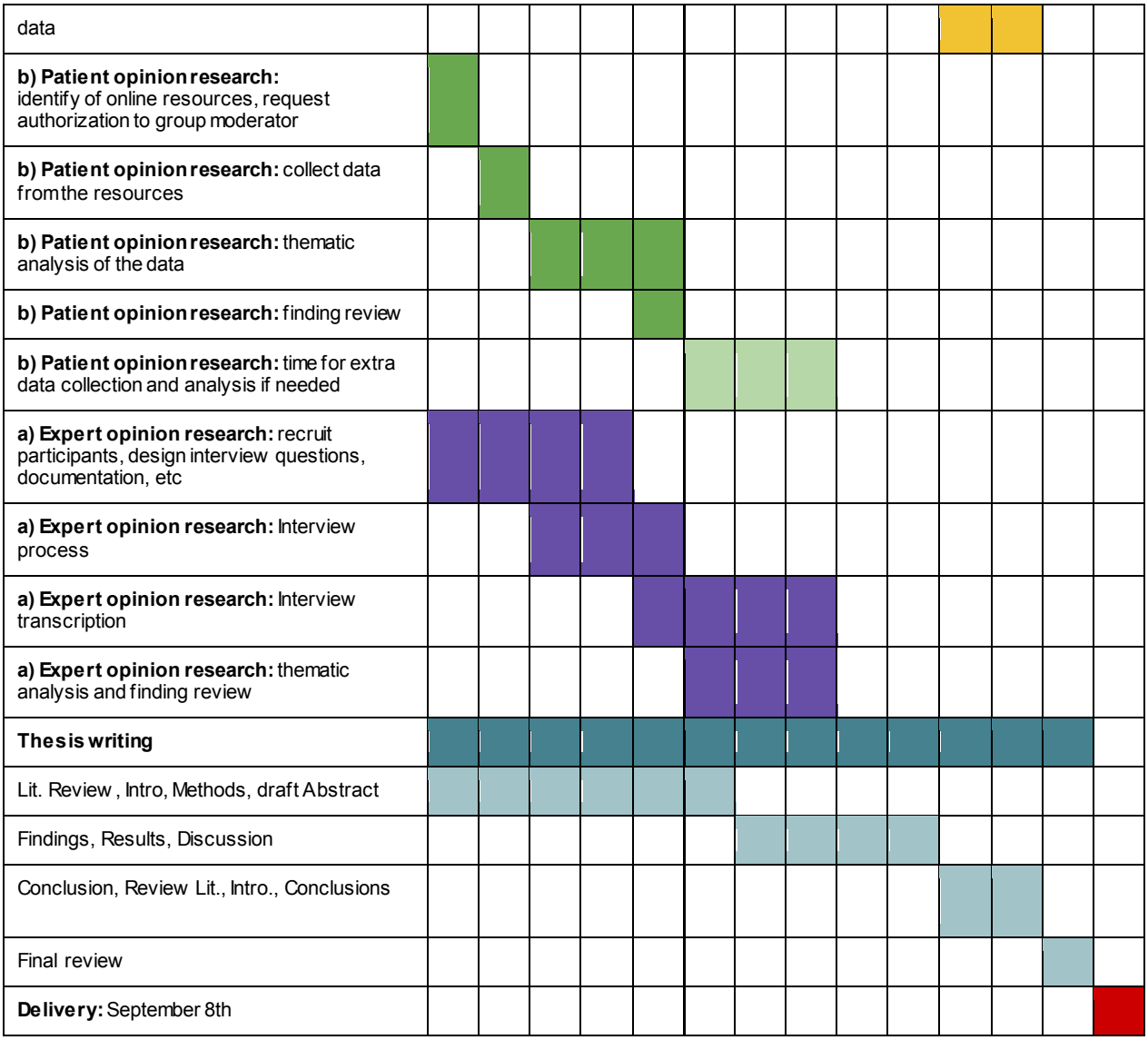
6. Thesis developing plan

In the developing timeline is considered a limited time for the literature review because the majority of the research was completed during the writing of the minor thesis that has a similar research topic. However, a further research in some extra subjects is required after the data analysis to evaluate the result.

Some time is reserved for the thematic analysis of the online resources and the interview of experts. Lastly, the writing process will be implemented for all the available time, however it will be a little more intense at the beginning and at the end of the available time. Final delivery date will be September 11th, 2017.

GANTT chart:

Month	June				July				August				Sept	
Week	I	II	III	IV	I	II	III	IV	I	II	III	IV	I	II
Literature review: relevant information collection+ literature review writing														
Literature review: update based on analysed														



Exit university (UCL) delivery deadline: Friday September 8th, 2017

7. Resources

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